

The Autism Friendly Initiative at Boston Medical Center:

Improving the Healthcare Experience for Patients with Autism

AUCD
April 2021



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Today's Objectives

- Understand aspects of medical care which may be difficult for patients with ASD
- Review strategies of optimizing care for patients with ASD
- Determine how participants might begin to address those challenges at their respective practices.



ASD



2 Visits

8 Visits



ASD



**3x
to 7x
more expensive**

National Survey of Children with Special Health Care Needs (NS-CSHCN)

- Parents of children with ASD report:
 - Higher levels of unmet medical needs
 - Significant difficulty using services
 - Lack of shared decision making and care coordination
 - Adverse family impact

Common Features of Autism that can be Barriers in Healthcare Settings:



Difficulties
with social
communication



Heightened preference
for routines, and
difficulties with
transitions and new
experiences



Sensitivity to
sensory stimuli



Difficulties
regulating
emotions and
behaviors

Sensory Overload

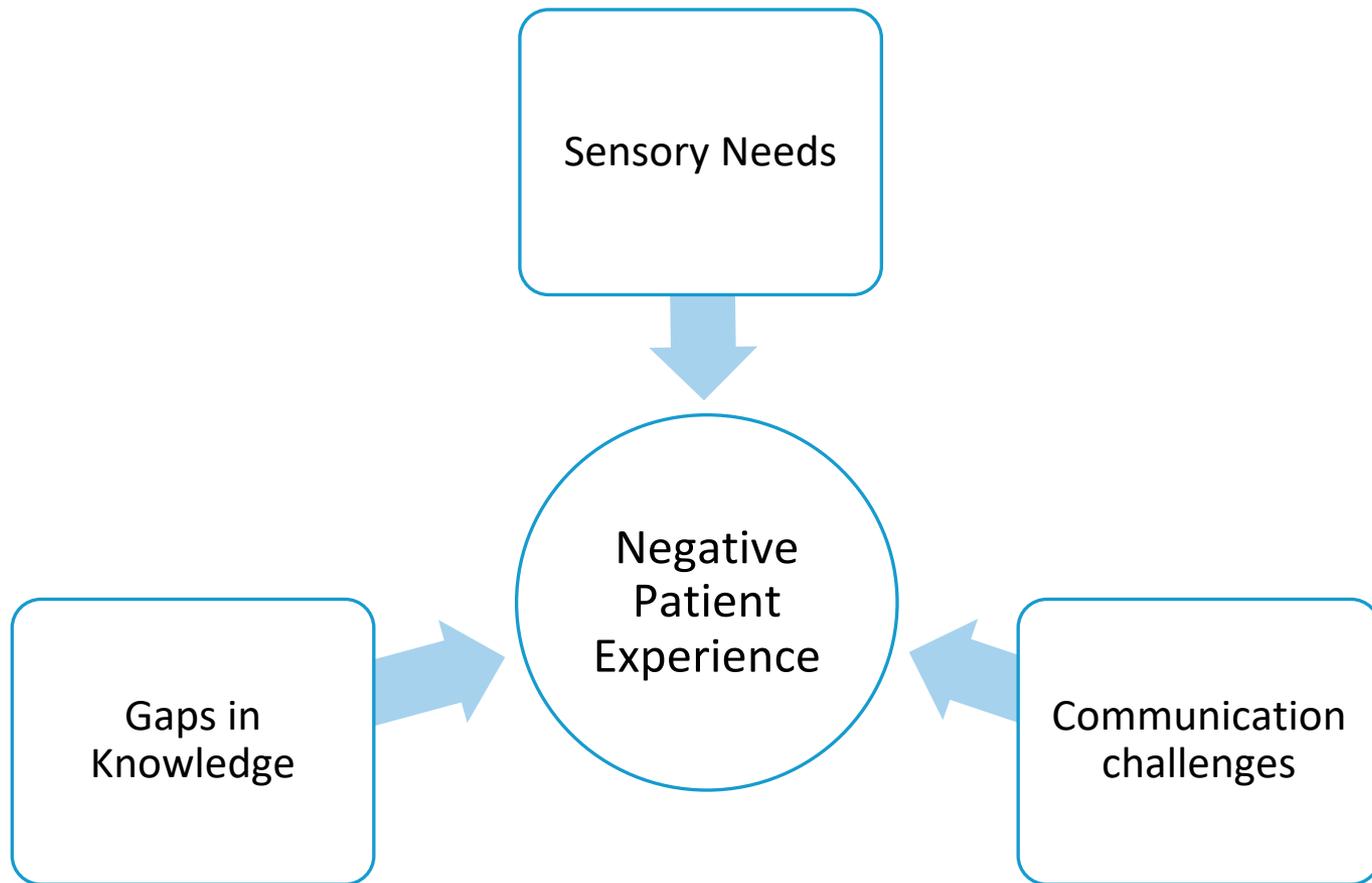
Unpredictability

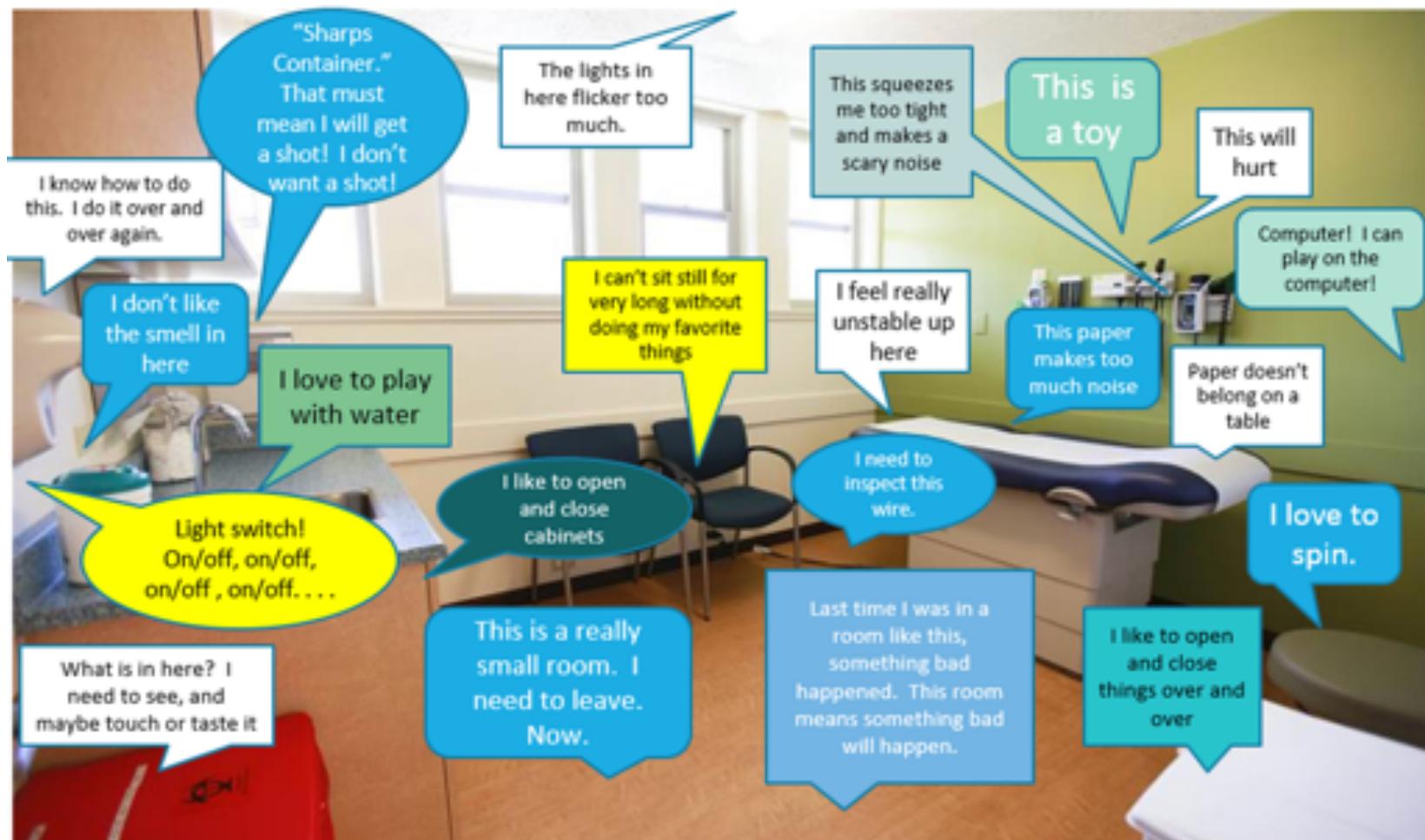
Quick Transitions

New People

Change in Routine

Communication
Challenges





I know how to do this. I do it over and over again.

I don't like the smell in here

"Sharps Container." That must mean I will get a shot! I don't want a shot!

I love to play with water

Light switch! On/off, on/off, on/off, on/off...

What is in here? I need to see, and maybe touch or taste it

The lights in here flicker too much.

I can't sit still for very long without doing my favorite things

I like to open and close cabinets

This is a really small room. I need to leave. Now.

This squeezes me too tight and makes a scary noise

This is a toy

This will hurt

Computer! I can play on the computer!

Paper doesn't belong on a table

This paper makes too much noise

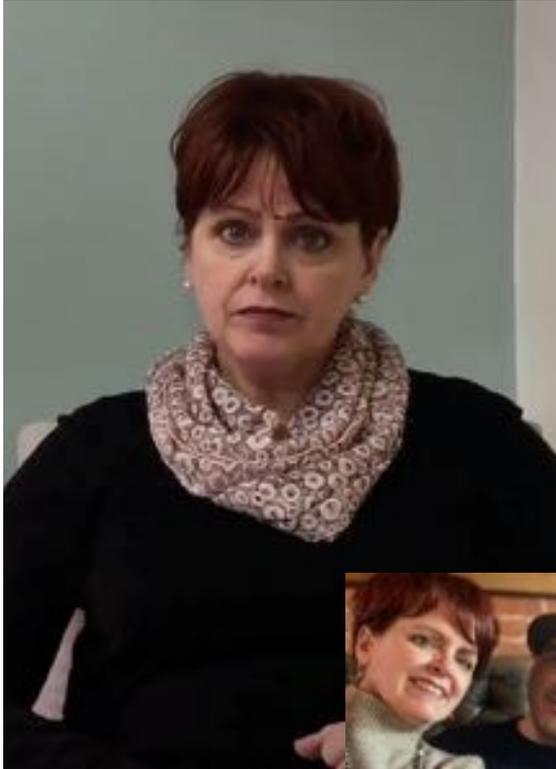
I feel really unstable up here

I need to inspect this wire.

Last time I was in a room like this, something bad happened. This room means something bad will happen.

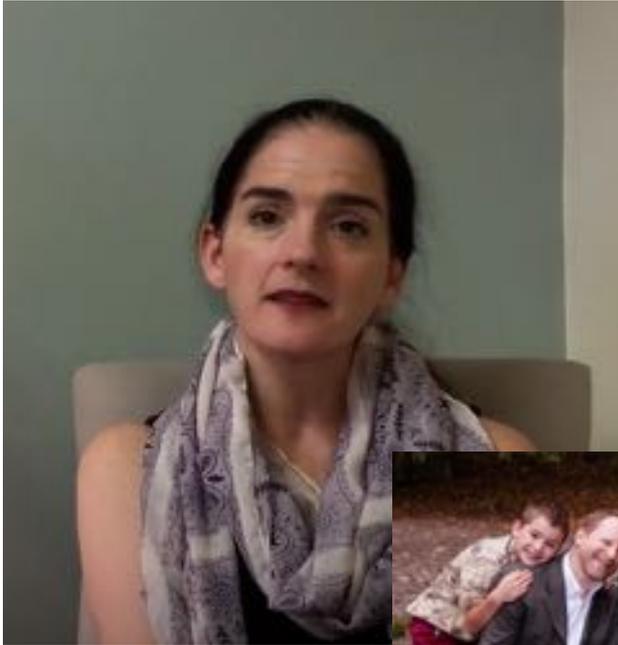
I love to spin.

I like to open and close things over and over



“I get stressed from the moment I wake up on the day of that appointment”

-Lucy, mother of 15 year old girl with autism and Down Syndrome



“It’s frustrating for me, as a parent, because I feel like I wasn’t listened to”

-Faith, mother of 7 year old boy with autism



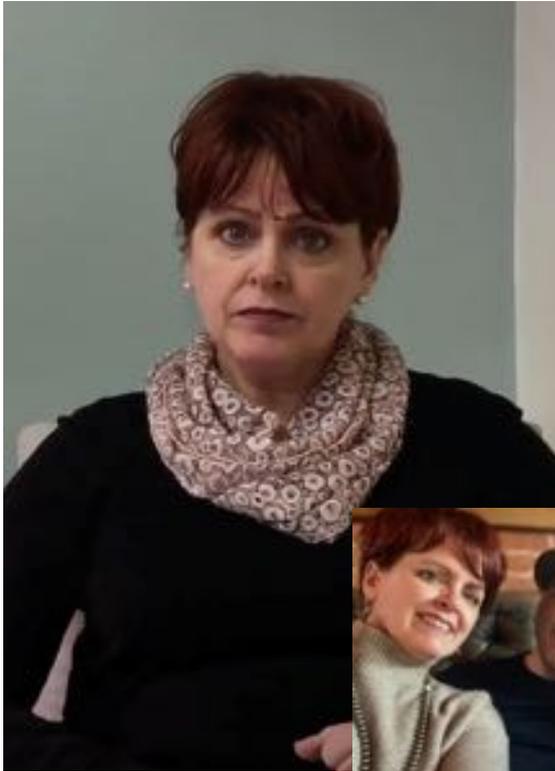
"All I could hear was Mason screaming,
and next thing I know, I found him in a
straightjacket"

-Liz, mother of 15 year old boy with
autism



“I couldn’t really process what was being said to me during the appointment, because I had to make sure my kid was safe”

-Jen, mother of 11 year old boy with autism



”...not only me trying to hold her down, but also another staff member trying to hold whatever I can’t hold, because she’s really strong, and then the other two [staff] trying to get the blood [draw]”

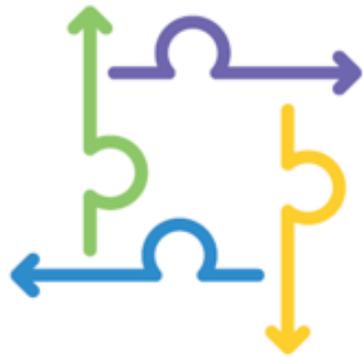
- Lucy, mother of 15 year old girl with autism and Down Syndrome



"My lack of knowledge on how to approach the care for a patient with ASD is limiting my ability to best provide services for him/her."



71%
**WANT
MORE
TRAINING**



**AUTISM
FRIENDLY
INITIATIVE**
at Boston Medical Center

The Autism Friendly Initiative at Boston Medical Center

- **Goal: Improve the overall hospital experience for patients with ASD and their families.**
- Provide clinicians and staff with the **tools, information, and training** needed to better support patients with ASD seen in the healthcare environment.
- Developed based on valuable **input from** various sources, such as key **stakeholders** (e.g., patients, families, researchers, clinicians), **literature review, and research/evaluation.**

Team



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Steering Committee (meets 2x/year)

A multidisciplinary group of hospital and community leaders that assists with strategic planning, decision-making, and overall optimization of the Initiative.

Quality Improvement Board (meets 6x/year)

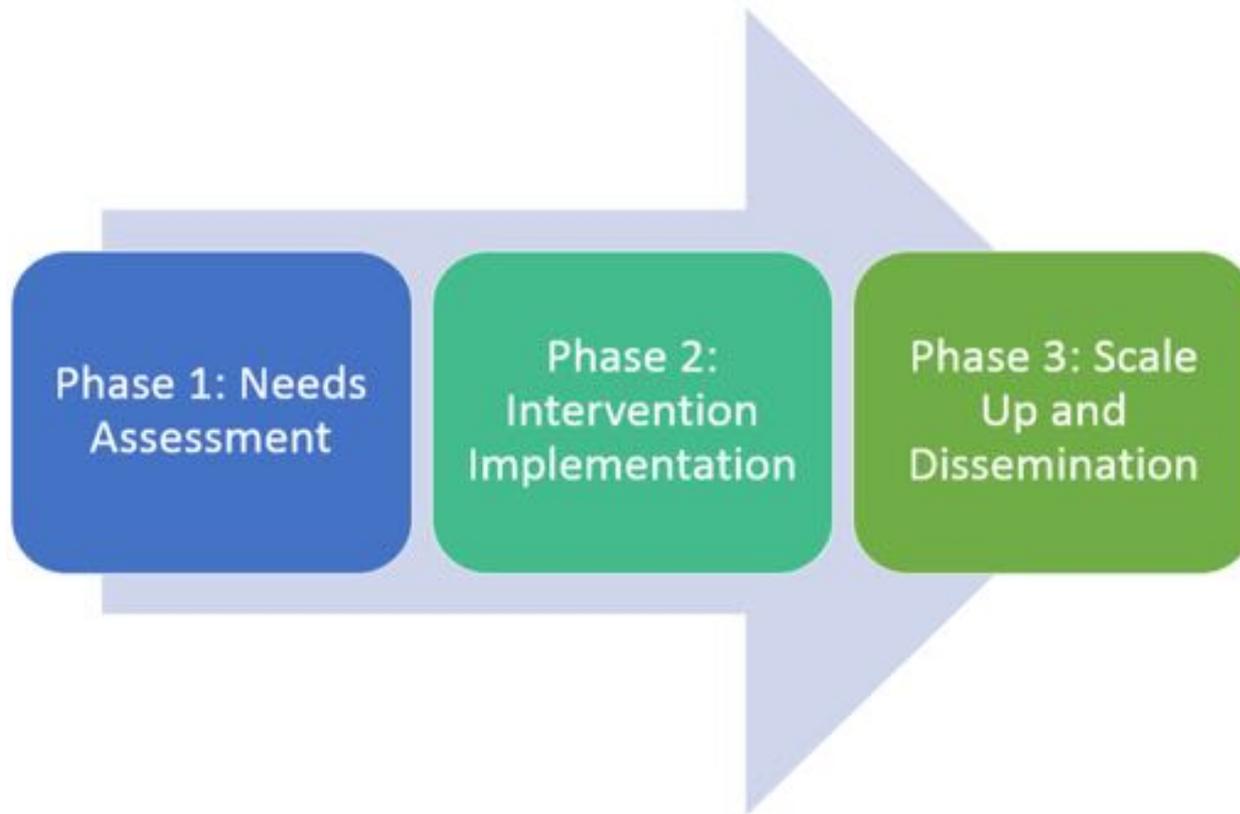
Provides guidance, support, and insight to ensure that interventions are driven by best practice.

Teens Educating, Advocating, and Consulting in Healthcare (TEACH) (meets 4x/year)

A group of patients who inform the development of Autism Friendly interventions based on their personal experiences.

Our Guiding Principles

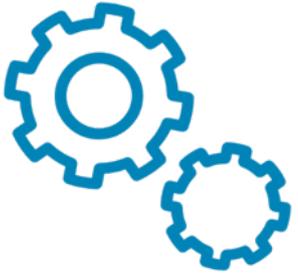
- Broad engagement of stakeholders
- Patient/family voice
- Strategic, multi-tiered interventions
- Real-time monitoring/evaluation
- Commitment to values





Phase 1: Needs Assessment

- Hospitalwide Staff Survey
- Parent focus group
- Literature review
- Ethnographic Study
- Patient Data Analysis



Phase 2: Intervention Implementation



Individualized Care

- The **Autism Support Checklist (ASC)** collects information about a patient's communication style, triggers, safety concerns, and de-escalation strategies.
 - Administered by phone
 - Summarized and entered into the patient's Electronic Medical Record (EMR).

The Autism Program
AT BOSTON MEDICAL CENTER

AUTISM FRIENDLY INITIATIVE
at Boston Medical Center

Autism Support Checklist

Patient Name: _____ Patient Date of Birth: _____

Date Collected: _____ Collected By: _____

Communication

1. Does the patient communicate using spoken language?

Yes
 No
Please explain: _____

2. What other ways does the patient communicate?

Pictures
 Written Words
 Device/Tablet
 Gestures/Signs
 Other: _____

3. What would help the patient understand information?

Spoken Language
 Written Words
 Device/Tablet
 Gestures/Signs
 Other: _____

Reason for Visit/Call

Chart Review

Encounters Surgeries Anesthesia Notes Labs Imaging Cardiology Procedures Meds LDAs Media Letters Episodes

Snapshot

- Care Everywh...
- Review Flows...
- Results Review
- Synopsis
- History
- Allergies
- Problem List
- Medications
- Immunizations
- Demographics
- Enter/Edit Res...

Patient Care Coordination Note

Wed Oct 10, 2018 12:13 PM

Please retain the Autism Support Checklist in the Care Coordination Note.

- **Communicates via:** non-verbal, gestures
- **Understands via:** spoken language
- **Communicates pain via:** crying/screaming, aggression
- **Understands procedures via:** demonstrating on another person, showing a picture schedule
- **Behaviors needing staff assistance:** bolting, self-injurious behaviors (sometimes throwing herself in the floor), hitting/kicking/etc.

For questions contact autismfriendlyinitiative@bmc.org

Patient

Recent Visits with You
[More...](#)

Allergies

Medications

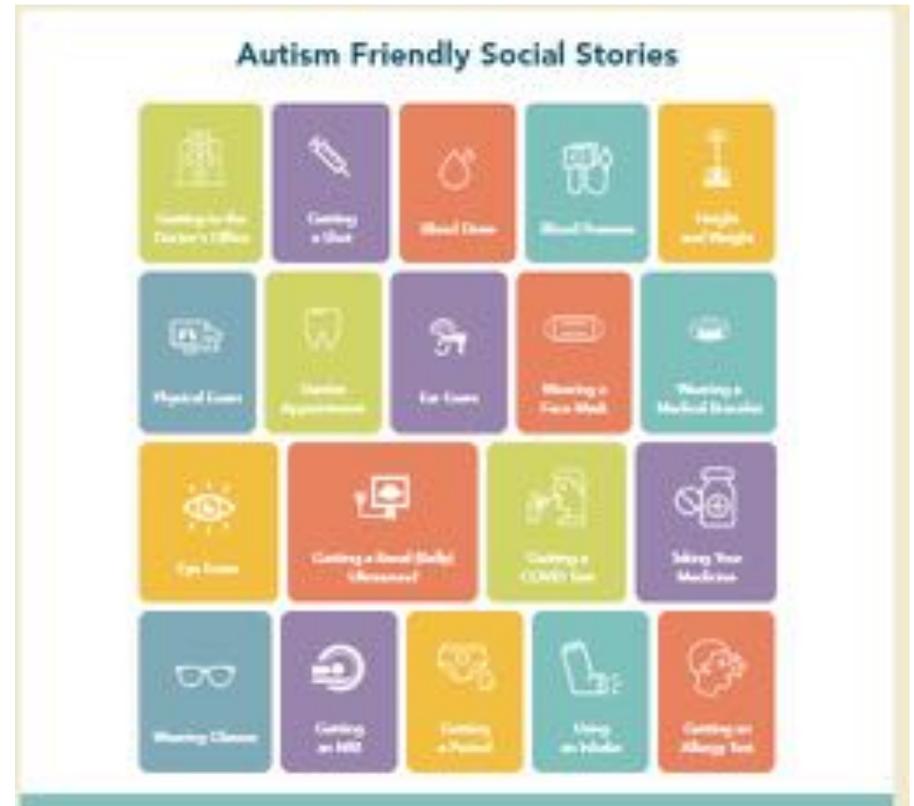
Preferred Pharmacies

Problem List

Other

Visit Preparation

- How can we prepare our patients and staff **before** the visit?
 - Social Stories ([check one out!](#))
 - Pre-Visit Phone Call
 - Pre-Visit Practice or Desensitization Opportunities



Case Example

- 14 year old female who needed an EEG for seizure activity
- History of significantly challenging and potentially dangerous behaviors during hospital visits, often involving security
- Preparation prior to visit
 - Record review and interviews
 - Use of visuals (social story and visual schedule)
 - Plan developed and shared with family & medical providers
- ARS support throughout visit to ensure environmental modifications are in place for patient & behavioral support
- Outcome: Successful visit!

Sensory Accommodations



"The toolpacks are just what they want - they think it's personalized to their family. It's the difference between their procedure getting done or not. They ask "You mean we get to keep it???" And the family was almost in tears because somebody took the time to put together something that the child would love." - Pedi Sedation, October 2020

"We got one of those little packs and I will tell you that everything was so perfect. I asked the mom if everything was appropriate because she mentioned that he was so sensitive to stimuli, and she thought they were all great. He especially loved the smiley ball and the tube that you pull. She commented that it was like it was meant just for him." - Radiology Tech, September 2020

"We have a 3 year old patient with ASD who struggles with getting his vital signs taken...the autism friendly sensory toolkit was hugely helpful in calming him down after the signs were taken!" - Pediatrician, March 2021

"These toolpacks have been a life saver for our kiddos with special sensory needs." - Child Life Specialist, October 2020

Education & Training

- Only 40% of US physicians are “very confident” in their ability to provide the same quality of care to patients with disabilities as to those without.
- Only 56% of US physicians “strongly agreed” that they welcomed patients with disabilities into their practice.
- BMC Survey:
 - 50% of respondents reported that they are not fully comfortable examining a patient with ASD
 - 48% of respondents reported that they were only moderately comfortable with their ability to communicate with a patient with ASD
 - 71% identified a need for more specific training

Education & Training

- The Autism Friendly Initiative at Boston Medical Center routinely trains the following cohorts at Boston University/Boston Medical Center:
 - Predoctoral Dental Students
 - Public Safety Officers
 - Medical Students
 - Medical & Dental Residents
 - Genetic Counseling Students
 - Interpreter Services
 - Individual clinics and teams as requested
- Medical simulation events for trainees and Boston Public School students
- Video series integrated into BMC's Employee Learning platform



Phase 3: Scale Up & Dissemination

- To date, we have participated in **20+** presentations and conferences.
- We are continuously studying and **evaluating** our interventions.
- We engage stakeholders and have maintained **partnerships** with dozens of other healthcare institutions nationwide
- Currently working on a Delphi study to inform **guidelines** for an **Autism Friendly healthcare practice**.

Ongoing Research:

- Autism Friendly Healthcare Delphi Study
- Hospital-wide Autism Resource Study
- TEACH Focus Group Study
- Emergency Department Qualitative Analysis Study
- Sensory Tools Effectiveness Study
- Autism Friendly Training Impact Study



Tips for Clinicians

1. Prepare your patient
2. Utilize caregiver knowledge
3. Practice flexibility & patience
4. Individualize care ***while presuming competence***
5. Accommodate communication needs
6. Be aware of sensory needs
7. Share your knowledge

What's next?

- At BMC:
 - Further development of our range of interventions to meet the ongoing needs of our patients, families, and providers.
 - Ensuring that such interventions are available to patients **of all ages** and **for all practice settings** (inpatient, outpatient, emergency, etc.).
- Beyond BMC:
 - Further dissemination and partnership around emerging best practices within this community

FYI:

We will be partnering with ITAC to deliver a training on
“Building an Autism Friendly Practice”
for DBP Programs,
which will allow for a more immersive discussion on
how healthcare practices can build their own roadmaps
to autism friendly care, regardless of practice size or setting.

If other programs have interest in a similar training, contact
Jczyzia@aucd.org

Stay Connected!



autismfriendly@bmc.org



(617) 414-4247



<https://www.bmc.org/visiting-us/autism-friendly-initiative>

Citations

Iezzoni LI, Rao SR, Ressalam J, Bolcic-Jankovic D, Agaronnik ND, Donelan K, Lagu T, Campbell EG. Physicians' Perceptions Of People With Disability And Their Health Care. *Health Aff (Millwood)*. 2021 Feb;40(2):297-306. doi: 10.1377/hlthaff.2020.01452. PMID: 33523739.

Vohra R, Madhavan S, Sambamoorthi U, St Peter C. Access to services, quality of care, and family impact for children with autism, other developmental disabilities, and other mental health conditions. *Autism*. 2014;18(7):815-826. doi:10.1177/1362361313512902